TITLE: Examining the effects of Activities of Daily Living (ADLs) on Informal Caregiver Strain

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Abstract

Objectives: This study examines the factors associated with caregiver strain (CS) experienced by informal caregivers of older people, using data from Ireland.

Methods: The analysis is based on a sample of 1,394 informal caregivers obtained from Ireland's Quarterly National Household Survey (2009). The Caregiver Strain Index (CSI) is used to measure CS on a scale from 0-13. The analysis focuses on estimating the association between caregiving activities (measured using Activities of Daily Living) and CS, using multivariate regression analysis.

Results: Overall, 60% of informal caregivers report feeling strained. The results suggest that different types of caregiving assistance are associated with increasing CS, in line with Pearlin's conceptual model of Stress Process theory and Process Utility theory of informal care. Female caregivers have significantly higher levels of strain. Moreover, CS amongst co-residential caregivers is 0.8 points higher compared to those who are non-resident. Conversely, caregivers over 65 years are less prone to strain than younger caregivers. The condition of the dependent is also a statistically significant factor: caring for someone with a physical condition, a mental condition, or both a physical and mental condition, increases CS.

Conclusions: As Ireland and Europe's populations are "greying", sustainable systems and supports need to be designed to meet demand for care that limit strain for caregivers. In doing so, policymakers and their advisors need to better understand the impact of informal caring on caregivers.

Keywords: caregivers' needs, informal caregivers, elder care

Introduction

Ageing populations, coupled with a growing burden of chronic disease, have significant implications for elder care provision across developed countries. Many older people prefer to remain (and die) in their own homes[1], and so family caregivers are important within the system of long-term care. Such care, referred to as informal care, is essentially provided 'free of charge', mainly by family members, to persons with long-term care needs[2]. This has social and economic implications for informal carers[3], who are in short supply and need to balance provision of informal care with their own needs and commitments.

A principal goal of informal care is to help the dependent person maintain the ability to perform basic activities (such as personal care, walking, getting in and out of bed, and taking medicines). These are known collectively as activities of daily living (ADLs). While the provision of informal care is positive for the dependent, helping to maintain their independence and well-being[4], far less is known about the impact of particular caregiving activities on the caregiver themselves. In this paper, we hypothesize and investigate an association between types of caregiving and caregiver strain (CS). The study measures the type of caregiving and examines the association with CS, measured using the Caregiver Strain Index (CSI).

The overall costs and benefits of informal care on caregivers are well debated in the literature. From an individual perspective, in cases where the expectations placed on caregivers are reasonable and adequate supports are provided, caregiving can be an enriching and rewarding experience[5], a source of happiness, and satisfaction, yielding positive impacts[3]. However, such positive outcomes are often dominated by the negative effects of caring[3]. Existing international research suggests that caregivers can feel burdened, and are at risk of psychological stress, health disorders, and increased mortality[6-8]. A review of literature in the area concluded that informal caregiving lowers the quality of caregivers' psychological health, which subsequently has a negative impact on physical health outcomes[3]. Much of the existing literature is focused on caring for dependents with a specific condition or disease and the effects are dependent on the type of care provided, the relationship with the dependent, the intensity of

caring provided and the number of years spent caring[3]. What is less well known is the impact of particular caregiving activities on the caregiver, and this is the focus of this paper.

Ireland provides a useful case study for examining CS owing to its impending ageing population and preference for informal care. Currently, 637,567 people in Ireland are aged 65 or over, accounting for 13.3% of the total population. This represents a 19.1% increase since 2011 and it is expected that by 2046 approximately 1.4 million individuals in Ireland will be over 65[9]. Informal care is the principal source of care for older dependents in Ireland, where 4.1% of the population are informal caregivers[9], and this informal care is complemented with some formal care services[10]. The economic value of informal care in Ireland ranges between €2.1 and €5.5 billion[11].

To date, research on CS in Ireland is limited[12, 13], and the employment of validated measures of strain (CSI) is sporadic and confined to hospital settings[14]. Given the recent financial crisis and persistent budgetary pressures, it is likely that the reliance on informal care will persist. The sustainability of this will depend on the degree to which CS can be minimized. To inform sustainable care planning, caregivers' needs and sources of CS should be identified and their effects considered in a meaningful manner[15, 16]. This paper examines what influences CS amongst informal caregivers providing elder care in Ireland, in particular examining the impact of the care being provided.

Methods

Relevant Theories

Brouwer et al[17] propose using Process Utility theory to examine the informal caregiving process, with the amount of care and tasks performed influencing utility. The utility derived from the process of caring may decline when tasks get more demanding and time consuming, thereby increasing the subjective burden of caregiving and decreasing caregivers' quality of life[17]. This complements Pearlin's[18] conceptual model of caregiver outcomes, which is based on Stress Process theory, which considers how factors associated with the change in roles and responsibilities associated with caring accumulate to cause stress[19]. Pearlin's model proposes that care demands and dependents' impairment characteristics are primary stressors and affect caregivers' outcomes[18].

In this paper, we empirically test these theories and examine how care demands and dependents' impairment affect caregivers' outcomes. In doing so we test the following hypotheses:

H1: there is an association between types of caregiving and caregiver strain (CS);

H2: dependents' limiting condition affects CS;

H3: there is an association between types of caregiving and the components of CS.

These hypotheses are tested whereby; caregiver strain (CS) is an outcome from stress and is measured here by the Caregiver Strain Index (CSI), type of care is measured using Activities of Daily Living (ADLs) and dependents' condition is a category of impairment.

Data

Data from Ireland's Quarterly National Household Budget Survey 2009 conducted by the Irish Central Statistics Office[20] is employed. In Quarter 3 it contained an ad hoc module specific to individuals who perform informal caring duties; this module has not been repeated since nor has similar been collected elsewhere more recently. An informal caregiver is defined by the help provided to others either living with the respondent or in another household[20]. Formally paid or professional caregivers are not included in this survey.

In the survey, 1,971 (9%) individuals indicated that they were a caregiver. As the focus of this study is on care provided to older people, caregivers caring for anyone under the age of 65 years were excluded from this study (n=577), leaving a sample size of 1,394 (6.5%). The survey results were weighted to agree with population estimates by age, sex and region[20].

The Caregiver Strain Index

The Caregiver Strain Index (CSI) was included in the survey questionnaire and is the instrument used for capturing CS in this analysis. The CSI is a 13-item instrument that measures strain related care provision from a multidimensional perspective[21]. This validated instrument (Chronbach's alpha 0.86) can be used to assess individuals of any age who have assumed the role of caregiver for an older adult[21].

It is considered a useful measure of CS when researching the effects of long-term care[22]. Caregivers were asked if their lifestyle has been affected by the caring that they provide and a list of 13 items were presented (Table 1). Caregivers indicate if their own life has been affected in any of those domains as a result of the caring duties they carry out (yes/no). The answers to the 13 questions are coded 1 for yes and 0 for no, thereby ending up with an ordered variable CS that ranges from 0 (no strain) to 13 (high strain). Positive responses to seven or more items on the index indicate a 'high' level of strain[21].

Type of care provided

Nine categories of type of care (known as Activities of Daily Living (ADLs)) are included in the caregivers' questionnaire (Table 2). Each caregiver was asked to indicate the categories of care provided to the dependent over and above what they would normally carry out for someone, of that age, living with them[20]. The nine ADL categories are not mutually exclusive.

Other independent variables

Data on caregivers' age is collected using 16 categories with four-year age gaps. W we categorized this information into four age groups (under 25, age25-44, age 45-64, over 65) for inclusion in the analysis. Sex is represented as a dummy variable (female = 1, male = 0). Four categorical variables summarize caregivers' marital status (married, never married, divorced/legally separated, and widowed). Caregivers are classified into three employment status groups (employed, unemployed, economically inactive).

Also included in the analysis are variables relating to caregiving. Three dummy variables pertaining to the relationship between dependent and caregiver (parent, spouse, and 'other' relationship) are included. We include a binary variable to indicate if the caregiver receives a financial allowance from the State. The number of hours spent caring is recorded as a categorical variable (1-14 hours, 15-28 hours, 29-42 hours, 43-56 hours, 57 or more hours, varies – under 15 hours, varies – over 15 hours). The 'varies – under 15 hours' is included in 1-14 hours category and the 'varies – over 15 hours' (n=57) is excluded from the analysis. We also control for the length of time a caregiver has assumed the caring role with three categories: less than 5 years, 5 to 10 years and more than 10 years. Another dummy variable

captures if the caregiver lives with the dependent. Finally, each dependent's limiting condition, and the reason they require care, is captured using five mutually exclusive categories, namely; physical, mental, both physical and mental, old age, and 'other'.

Analysis

To investigate the factors leading to increased CS this research employs a number of statistical and econometric analyses using STATA Version 14. Bivariate statistical analysis allows us to examine caregivers reporting different lifestyle changes that lead to strain and the type of care they specifically provide. To test the hypotheses, and further explore the relationship between strain and type of care, econometric analyses (negative binomial and probit regressions) were performed.

(i) Negative binomial regression

To test hypotheses H1 and H2 we use an econometric analysis that estimates the factors that affect CS using a negative binomial regression model. As the dependent variable, in this model CS (measured on a scale from 0-13), can only take on non-negative integer values and is heavily skewed (with a large proportion of zero values), count models are deemed most appropriate as they assume a skewed distribution and restrict predicted values to non-negative values[23-25]. A negative binomial model is favoured over the Poisson model owing to: 1) the assumption of equal mean and variance of the dependent variable (mean: 3.21, var: 14.07) is violated; 2) the Poisson model yields a large goodness of fit chi-squared value; 3) presence of overdispersion (alpha is significantly different from zero). We also computed effect sizes on the natural scale by calculating the sample average marginal and incremental effects[23].

(ii) Probit regressions

Probit regression models were also estimated using each component of the CSI as dependent variables. Thirteen probit models are estimated using these binary dependent variables. This allows us to treat each component of strain independently and estimate the effects of the ADLs, caregiving and personal and socio-economic variables; thereby testing hypothesis H3.

Results

Summary statistics

Preliminary data analysis (Table 3) reveals that 60% of the sample of caregivers report 'strain'. Of these, 35% score a 7 or higher suggesting high level of CS[21]. The majority of caregivers in the sample are female (70%), 45% are aged between 25 and 44, 48% report being in employment and 39% provide 15 or more hours of care per week. Over half are caring for a parent or spouse and 24% live with the dependent. About 70% of caregivers are caring for 1-5 years. Just 8% are in receipt of caregivers' allowance/benefit from the state (this is means tested and so many caregivers do not qualify). The dependents require care owing to old age (52%), physical affect/condition (30%), physical and mental affect/condition (9%), mental affect/condition (4%) and 'other' affect (5%).

The mean ADLs provided is 5.6 (standard deviation = 2.1) (see footnote to Table 2). In more detail, 16.6% of caregivers provide help with between 1 and 3 ADLs, 48% with between 4 and 6 ADLs and 35% between 7 and 9 ADLs. While it could be suggested that three of the ADLs, 'keeping him/her company', 'taking him/her out' and 'keeping an eye on him/her to see he/she is alright' are highly correlated, the correlation coefficients are all low (r <=.3), and so caregivers appear to distinguish between these three types of care.

Table 4 presents a matrix of caregivers who report each type of strain and each type of care activity, reported in percentages. Providing all types of care (i.e. all ADLs) contributes to financial strain and strain arising from work adjustments. It suggests that over 70% of respondents that report strain arising from work adjustment provide care for each ADL. Meanwhile, over 75% of those providing care related to 'other practical help', 'keeping him/her company', 'taking him/her out' and 'keeping an eye on' report having each of the strain components: disturbed sleep, physical strain, emotional adjustments, upsetting behaviour, work adjustments, overwhelming and other lifestyle. Financial strain is reported by over 78% of respondents providing all types of care (i.e. across all ADLs). Amongst those providing personal care less than 40% indicate they experience the following categories of strain: confining and

family adjustments. Also, amongst those giving medicines only 39% report on the constraining component of CSI and 42% on the family adjustments component of CSI.

Negative binomial regression results

The negative binomial regression (Table 5) indicates that all nine ADLs significantly increase CS. Helping with personal care, providing physical help, helping with paperwork/financial matters, taking the dependent out, administering medicines and 'other' help are found to be the most statistically significant (1% level); and are each negatively associated with CS. These activities also have large marginal effects (see column 4 on Table 5) on increasing CS on the 0 to 13-point CSI scale; physical help by 1.262 points, 'other help' 1.209 points, help with paperwork/financial matters by 1.188 points and giving medicine by 1.120 points. Therefore, we cannot reject hypothesis H1 as an association between types of caregiving and CS has been established.

Compared with the 'condition' of old age, CS is 1.214 points higher in those caring for a dependent who has a physical condition, 3.794 points higher when the dependent has a mental condition, 2.38 points higher if the dependent has both a physical and mental condition. Therefore, we cannot reject hypothesis H2: dependents' limiting condition does affect CS.

The results further suggest that if the caregiver is a close relative of the dependent it significantly increases CS. If the caregiver is caring for either a spouse or a parent, they experience higher strain by 0.337 points and 0.365 points respectively. This is compared with those caring for another relative or friend.

Those providing between 1 and 14 hours of care per week report 1.47 points less CS compared with providing between 29 and 42 hours per week *ceteris paribus.* CS amongst those living with the dependent is 0.811 points higher compared to those who are not living with the dependent, signalling they are prone to higher levels of CS.

The model controls for a number of personal and socio-economic characteristics; namely age, sex, marital status and employment status. The results further suggest that caregivers in full-time employment are more prone to strain by 0.565 points, than those out of the labour force, holding all else equal. Female caregivers experience higher strain by 0.719 points compared with male caregivers. Compared with those aged between 25 and 44, older caregivers (65 and over) are significantly less likely to report higher strain by as much as 1.442 points, *ceteris paribus*.

Interactions between sex and ADLs, and between employment and ADLs, are potentially interesting. However, all interaction terms were statistically insignificant in the regression models estimated and were therefore excluded from the final model estimation.

Probit regression results

To test hypothesis H3, the factors influencing the probability of each component of CS was investigated using probits and estimating marginal effects (Table 6).

If a caregiver provides personal care they were 41% more likely to experience disturbed sleep and almost 60% more likely to find it a physical strain, than those not providing personal care. Caregivers that physically help the dependent were 50% more likely to find it a physical strain, 46% more likely to find some behaviour upsetting and 50% more likely to experience 'other' lifestyle adjustments, than those who do not provide physical help. This type of care was also found to be 43% more upsetting for the caregiver, as they find the dependent has changed so much from their former self. Providing help with paperwork or other financial matters was found to be inconvenient (42%), confining (43%) and overwhelming (42%) for caregivers, than those not providing help with paperwork/other financial matters. Caregivers that administer medicine to the dependent were 42% more likely to experience disturbed sleep and financial strain, than those not administering medicine. Keeping the dependent company seems to have had the least significant effect on the components of CS. It was found to be insignificant for all components of strain except for where the caregiver finds it upsetting that the dependent has changed so much from his/her former self (10% level). Thus, we cannot reject

hypothesis H3, and conclude that an association between types of caregiving and the components of CS exists.

Discussion

It is likely there will be a greater reliance on caregivers in the future, given ageing populations, a rising burden of chronic disease and the always present need to prioritise service delivery given that resources are scarce. Caregivers frequently report stress and emotional strain which, in turn, are linked to a greater likelihood of caregivers reporting that their own health has suffered and/or quality of life has deteriorated[3]. In line with previous studies, this study reveals that informal caregivers in Ireland are prone to more strain if they are providing help with ADLs, or if they are female, or working, or caring for a parent or spouse.

A key contribution of this study was the investigation into the association between caregiving activities (measured using ADLs) and CS, controlling for personal characteristics and caregiving variables. The econometric analyses performed here estimated the relationship between specific ADLs and CS and its components, exploring the relationship between stressors and caregivers' outcomes. The results suggest that different types of caregiving assistance are associated with increasing CS, in line with Pearlin's conceptual model of Stress Process theory[18] and Process Utility theory of informal care[17]. Thus, while current financial supports (in form of a caregivers' allowance and respite grants) are useful in providing compensation and recognition for caregivers, they are not the only support policy available[26]. Targeted supports to ease CS - associated with providing medicines, financial matters etc. - should be considered. This may require better communication between caregivers and professional health care providers; information and educational initiatives etc. For example, previous Irish research indicates that training for informal caregivers contributes to reducing care burdens and may facilitate sustainability[27] of informal care provision in Ireland.

The analysis used a unique dataset that captures the extent and type of care being provided to older people, adding to the existing literature. Rather than limiting the analysis by condition of the dependent as per other studies, this analysis controlled for the dependents' condition, thus, advancing what is

currently known about CS. However, we acknowledge it is reliant on cross-sectional data from 2009. This limits the depth and scope of the analysis for investigating reverse causality etc. that would be feasible with panel data and were we able to construct instrumental variables. Nevertheless, in the absence of panel data, it was the best available at this time. A more recent longitudinal survey of those aged over 50, the Irish Longitudinal Study on Ageing (TILDA) data[28] is available. However, this is confined to those over 50 years of age and does not collect information on CS. Furthermore, there has been no addition to the type of supports provided to informal caregivers in the intervening period. We also acknowledge the limitations of the study's reliance on one measure of strain, CSI. While it is a brief and easily administered instrument with proven reliability and validity, it is limited by the lack of corresponding subjective rating[29] and long-term caregivers have criticized its dichotomous nature[22]. Nevertheless, it can effectively identify who may benefit from more in-depth assessment and follow-up[29], which is key for care planning and informing policy[14].

Obviously, the environment where the informal caring is taking place matters, owing to availability of supports, among other factors. Thus, country-specific analyses, such as this one, are imperative and should be considered when designing policy. Policies that aim to create sustainable long-term care systems is an important challenge for most high-income countries[16]. Evidence demonstrates that when social policy and care systems are appropriate, caregiving has a less detrimental effect, as experienced in Nordic countries [30]. To date, Irish research on caregivers is limited, and given the recent financial crisis, combined with rising incidence of chronic conditions, ageing population, and preference for informal care, it is crucial that long-term care is sustainable. In designing systems and supports to sustain this, whilst maintaining dignity and independence of dependents, policymakers need to understand the responsibilities and challenges borne by caregivers and their impacts. We acknowledge such calls to action are not new, but they are persistent [16,17,27]. This study provides quantifiable, measurable evidence which further supports recommendations to provide better systems and supports for caregivers and those being cared for.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Table 1: Carer Strain Index: Percentage of Carers and the Type of Strain Experienced

Category of Strain	Description	% of carers
Disturbed Sleep	Sleep is disturbed (e.g., because care recipient is in and out of bed or wanders around at night)	22%
Inconvenient	It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)	28.9%
Physical Strain	It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)	21.1%
Confining	It is confining (e.g., helping restricts free time or cannot go visiting)	39.1%
Family Adjustments	There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)	37.2%
Change to personal plans	There have been changes in personal plans (e.g., had to turn down a job; could not go on holiday)	33.6%
Emotional adjustments	There have been emotional adjustments (e.g., because of severe arguments)	20.4%
Upsetting behaviour	Some behaviour is upsetting (e.g., because of incontinence, care recipient has trouble remembering things, or care recipient accuses people of taking things)	21.4%
Upsetting Changes	It is upsetting to find care recipient has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)	31.9%
Work Adjustments	There have been work adjustments (e.g., because of having to take time off)	16.4%
Financial Strain	It is a financial strain	22.0%
Overwhelmed	Feeling completely overwhelmed (e.g., because of worry about care recipient; concerns about how you will manage)	28.9%
Other lifestyle	Other effects on lifestyle	21.1%

Source: QNHS (2009)
Notes: The question in the survey was "Has your own lifestyle been affected by the caring that you provide to <Depend> in any of the following ways?" Respondents were instructed to 'tick all that apply'.

Table 2: Description of Activities of Daily Living (ADLs)

Category of Care (ADL)	**Examples of type of care provided**	**% carers**
Personal care	Dressing, bathing, feeding, using the toilet, shaving	34.8%
Physical help	With walking, getting up/down stairs, getting in/out of bed	40.6%
Helping with paperwork or financial matters	Filling forms, banking, bills	57.3%
Other practical help	Preparing meals, shopping, laundry, housework	83.9%
Keeping him/her company	Visiting, sitting with, reading to, talking to	90.1%
Taking him/her out	Take for a drive, visit friends or relative	77.6%
Giving medicines	Make sure takes pills, give injections, change dressings	43.1%
Keeping an eye on him/her to see he/she is all right		90.5%
Other types of help	Not specified	43.4%
Number of ADLs performed^		**N (%)**
0		3 (0.22)
1-3		231 (16.57)
4-6		670 (48.06)
7-9		490 (35.15)

Source: QNHS (2009) **Notes**: The question in the survey was "What kinds of things do you usually do for <Depend> over and above what you would normally do for someone living with you? Do you usually help with:….(categories and examples as above were provided)" Respondents were instructed to 'tick all that apply'.
^: n=1394, min = 0, max = 9, mean = 5.6, std. dev. = 2.1

Table 3. Descriptive Statistics

Dependent Variable Description	**Mean (std dev)**
Caregiver Strain Index (min 0 – max 13)	3.21 (3.75)
Independent Variables Description	**N (%)**
Activity of Daily Living (ADL) Provided	
Provides personal care (yes/no)	485 (35)
Provides physical help (yes/no)	566 (41)
Provides help with paperwork or financial matters (yes/no)	799 (57)
Provides 'other' (unspecified) practical help (yes/no)	1170 (84)
Keeps the dependent company (yes/no)	1257 (90)
Takes the dependent out (yes/no)	1083 (78)
Administers medicines (yes/no)	601 (43)
Keeps an eye on the dependent to see he/she is all right (yes/no)	1262 (90)
'Other' (unspecified) types of help provided (yes/no)	606 (43)
Dependent Characteristics	
Dependent requires care due to a physical disability/limiting condition (yes/no)	415 (30)
Dependent requires care due to a mental disability/limiting condition (yes/no)	56 (4)
Dependent has both physical and mental disability/limiting condition (yes/no)	131 (9)
Dependent requires care due to age related limiting conditions (yes/no)	722 (52)
Dependent requires care due to 'other' (unspecified) limiting conditions (yes/no)	70 (5)
Dependent is a parent (yes/no)	649 (47)
Dependent is a spouse (yes/no)	145 (10)
Dependent is another relative/friend (yes/no)	600 (43)
Caregiving Variables	
Receives a carer's allowance/benefit (yes/no)	112 (8)
Caring for <= 5 years (yes/no)	968 (69)
Caring for 5 - 10 years (yes/no)	272 (19)
Caring for >= 10 years (yes/no)	154 (11)
Lives with the dependent (yes/no)	337 (24)
*Hours Spent Caring^*	
<= 14 hours per week (yes/no)	798 (57)
15 - 28 hours per week (yes/no)	220 (16)
29 - 42 hours per week (yes/no)	73 (5)
> =42 hours per week (yes/no)	246 (18)
Carers' Employment Status	
Employed	671 (48)
Unemployed	90 (6)
Economically inactive	633 (45)
Sex and Age of Carer	
Carer is female	982 (70)
<25 years	56 (4)
25-44 years	634 (45)
45-64 years	542 (39)
>=65 years	162 (12)

Marital Status	
Married	918 (66)
Never Married	312 (22)
Separated/divorced	93 (7)
Widowed	71 (5)

Notes: N = 1394, ^4% of respondents indicated that they provided more than 15 hours per week but that number varies per week and so it was not possible to assign to one of the categories.

Table 4. Components of Caregiver Strain by Activities of Daily Living

ADLs	Category of Strain												
	Disturbed Sleep	Inconvenient	Physical Strain	Confining	Family Adjustments	Change to personal plans	Emotional adjustments	Upsetting behaviour	Upsetting Changes	Work Adjustments	Financial Strain	Over-whelmed	Other lifestyle
Personal care	55%	52%	54%	36%	39%	44%	64%	62%	45%	72%	78%	68%	62%
Physical help	60%	57%	59%	40%	42%	47%	67%	64%	49%	73%	80%	72%	64%
Paperwork or financial matters	69%	61%	71%	47%	52%	55%	74%	71%	58%	78%	84%	77%	71%
Other practical help	75%	68%	76%	56%	59%	62%	77%	77%	65%	82%	88%	81%	76%
Keeping him/her company	77%	70%	78%	59%	61%	65%	78%	77%	66%	83%	89%	82%	78%
Taking him/her out	76%	68%	76%	56%	58%	62%	77%	76%	65%	81%	87%	81%	76%
Giving medicines	59%	56%	62%	39%	42%	48%	67%	65%	50%	74%	80%	70%	64%
Keeping an eye on	76%	70%	77%	58%	61%	64%	78%	78%	66%	82%	88%	82%	77%
Other practical help	75%	68%	76%	56%	59%	62%	77%	77%	65%	76%	82%	75%	62%

Source: QNHS (2009) **Notes:** The categories of caregiver strains appear in columns 2 to 14. There is no ordering to the severity of the strains. They are as they appear in the survey. The type of care provided, classified by ADL, are presented in column 1. A matrix of caregivers reporting each type of strain and each type of care activity are contained in this table, reported in percentages.

Table 5. Determinants of Caregiver Strain Estimated Using Negative Binomial Regression

	Coefficient	Robust Std Err	Marginal Effects dy/dx
Activities of Daily Living			
Personal Care	0.226***	0.078	0.758***
Physical help	0.377***	0.078	1.262***
Paperwork/financial matters	0.355***	0.077	1.188***
Practical help	0.223*	0.123	0.746*
Keep company	0.258**	0.131	0.865**
Take out	0.295***	0.093	0.989***
Give medicine	0.334***	0.077	1.120***
Keep eye on dependent	0.329**	0.146	1.102**
Other help	0.361***	0.068	1.209***
Dependent condition			
Physical condition	0.363***	0.075	1.214***
Mental condition	1.133***	0.181	3.794***
Physical and mental condition	0.711***	0.086	2.380***
Other affect	0.286	0.183	0.958
Relationship to Dependent			
Parent	0.337***	0.077	1.129***
Spouse	0.365***	0.123	1.221***
Caregiving variables			
Care Time <14 hrs per week	-0.439***	0.114	-1.470***
Care Time 15-28 hrs per week	-0.033	0.11	-0.112
Care Time >43 hrs per week	-0.043	0.104	-0.143
State allowance received	0.021	0.104	0.071
Caring for <5 years	0.046	0.079	0.155
Caring for > 10 years	0.169	0.111	0.566
Live with dependent	0.242**	0.104	0.811**
Caregiver characteristics			
Employed	0.169**	0.073	0.565**
Unemployed	0.124	0.163	0.416
Female	0.215***	0.076	0.719***
<25 years	-0.116	0.209	-0.389
45-64 years	-0.08	0.071	-0.266
>=65 years	-0.431***	0.135	-1.442***
Constant	-0.355***	0.261	
N	1394		
R2	0.115		0.758

Notes: ***significant at the 1% level, ** significant at the 5% level, * significant at the 10% level
Dependent variable is Caregiver Strain (0 -13). Reference categories: a dependent classified as having the condition 'old age', 'other' relationship to dependent, care time 29-42 hours, caring 5 to 10 years, carer is economically inactive 15-64 years, male, aged between 25 and 44. Marital status and the interaction terms FemaleADL and EmploymentADL were found to be insignificant and subsequently removed from the final model. Sampling weights have been applied.

Table 6. Marginal Effects of Probit Regressions

	Disturbed sleep	Inconvenient	Physical strain	Confining	Family adjustments	Changes to personal plans	Emotional adjustments	Upsetting behaviour	Upsetting changes	Work adjustments	Financial strain	Over-whelmed	Other lifestyle
	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)	b(se)
Personal care	0.416*** (0.114)	0.260** (0.102)	0.577*** (0.115)	0.247** (0.102)	0.250** (0.102)	0.211** (0.103)	0.201* (0.111)	0.202* (0.112)	0.361*** (0.102)	0.185 (0.122)	0.416*** (0.114)	0.260** (0.102)	0.577*** (0.115)
Physical help	0.288** (0.114)	0.222** (0.1)	0.508*** (0.117)	0.245** (0.098)	0.346*** (0.098)	0.324*** (0.099)	0.248** (0.109)	0.460*** (0.109)	0.430*** (0.099)	0.322*** (0.118)	0.288** (0.114)	0.222** (0.1)	0.508*** (0.117)
Paperwork/ financial matters	0.343*** (0.107)	0.422*** (0.089)	0.185* (0.109)	0.430*** (0.087)	0.252*** (0.087)	0.356*** (0.089)	0.099 (0.1)	0.274*** (0.099)	0.296*** (0.089)	0.278** (0.11)	0.343*** (0.107)	0.422*** (0.089)	0.185* (0.109)
Practical help	0.036 (0.161)	0.082 (0.127)	0.053 (0.173)	0.263** (0.128)	0.174 (0.126)	0.279** (0.131)	0.228 (0.153)	-0.02 (0.14)	0.062 (0.127)	0.21 (0.167)	0.036 (0.161)	0.082 (0.127)	0.053 (0.173)
Keep company	0.192 (0.2)	-0.105 (0.154)	0.06 (0.21)	0.146 (0.164)	0.214 (0.164)	0.094 (0.166)	0.209 (0.19)	0.305 (0.192)	0.324* (0.173)	-0.072 (0.206)	0.192 (0.2)	-0.105 (0.154)	0.06 (0.21)
Take out	-0.117 (0.13)	0.083 (0.11)	0.265* (0.144)	0.305*** (0.112)	0.270** (0.11)	0.293*** (0.114)	0.117 (0.125)	0.055 (0.121)	0.043 (0.11)	0.321** (0.147)	-0.117 (0.13)	0.083 (0.11)	0.265* (0.144)
Give medicine	0.421*** (0.112)	0.212** (0.098)	0.181 (0.116)	0.292*** (0.095)	0.291*** (0.096)	0.186* (0.097)	0.290*** (0.107)	0.233** (0.108)	0.261*** (0.098)	0.203* (0.115)	0.421*** (0.112)	0.212** (0.098)	0.181 (0.116)
Keep eye on dependant	0.213 (0.217)	0.142 (0.162)	0.347 (0.241)	0.325* (0.169)	0.249 (0.168)	0.221 (0.172)	0.156 (0.193)	0.11 (0.186)	0.338* (0.175)	0.33 (0.237)	0.213 (0.217)	0.142 (0.162)	0.347 (0.241)
Other help	0.143 (0.097)	0.321*** (0.083)	0.390*** (0.099)	0.188** (0.083)	0.335*** (0.083)	0.367*** (0.083)	0.305*** (0.092)	0.188** (0.092)	0.164* (0.085)	0.283*** (0.099)	0.143 (0.097)	0.321*** (0.083)	0.390*** (0.099)
_cons	-2.750*** (0.37)	-1.675*** (0.29)	-3.055*** (0.401)	-2.277*** (0.306)	-2.112*** (0.306)	-2.087*** (0.306)	-2.676*** (0.352)	-2.251*** (0.337)	-2.597*** (0.318)	-2.785*** (0.384)	-2.750*** (0.37)	-1.675*** (0.29)	-3.055*** (0.401)
chi2	486.934	319.886	514.889	533.986	497.171	465.723	301.539	344.802	439.297	291.008	486.934	319.886	514.889
r2_p	0.331	0.191	0.358	0.286	0.27	0.262	0.214	0.238	0.252	0.234	0.331	0.191	0.358
bic	1192.853	1566.609	1131.312	1541.635	1553.351	1523.422	1317.838	1314.487	1516.741	1161.069	1192.853	1566.609	1131.312

Source: QNHS (2009) **Notes**: ***significant at the 1% level, ** significant at the 5% level, * significant at the 10% level (& Shaded). All models have controlled for dependent condition, carer relationship to dependent, hours caring, years caring, co-resident, if carer receives an allowance, employment status, carers (results available on request). N = 1394.

REFERENCES

1. Tarricone R, Tsouros, A.D. Home care in Europe: the solid facts. WHO Regional Office Europe, 2008.
2. Care Alliance Ireland. The right not to be called an Informal Carer. In: Ireland CA, (ed.). 2017.
3. Bauer JM and Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *Journal of Population Ageing*. 2015; 8: 113-45.
4. Covinsky KE, Palmer RM, Fortinsky RH, et al. Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: increased vulnerability with age. *Journal of the American Geriatrics Society*. 2003; 51: 451-8.
5. Care Alliance Ireland. Fact Sheet on Family Caring In Ireland - June 2015. *Guiding support for family carers*. Care Alliance Ireland, 2015.
6. Mentzakis E, McNamee P and Ryan M. Who cares and how much: exploring the determinants of co-residential informal care. *Review of Economics of the Household*. 2009; 7: 283-303.
7. Pinquart M and Sörensen S. Correlates of physical health of informal caregivers: a meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2007; 62: P126-P37.
8. Schulz R and Monin JK. The costs and benefits of informal caregiving. In: Brown SL, Brown, R.M., Penner, L.A., (ed.). *Moving beyond self-interest: Perspectives from evolutionary biology, neuroscience, and the social sciences*. New York: Oxford University Press, 2012, p. 178-98.
9. Central Statistics Office. 2016 Census Results. 2017.
10. Larragy JF. Formal service provision and the care of the elderly at home in Ireland. *Journal of Cross-Cultural Gerontology*. 1993; 8: 361-74.
11. Hanly P and Sheerin C. Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary. *The Economic and Social Review*. 2017; 48: 337-64.
12. Blackwell J, O'Shea E, Moane G and Murray P. *Care provision and cost measurement: dependent elderly people at home and in geriatric hospitals*. Economic and Social Research Institute (ESRI), 1992.
13. O'shea E. Costs and consequences for the carers of people with dementia in Ireland. *Dementia*. 2003; 2: 201-19.
14. Care Alliance Ireland. Family Caring in Ireland 2013.
15. Norton EC. Long-Term Care. Handbook of Health Economics, Volume 1, Edited by AJ Culyer and JP Newhouse. Elsevier Science BV, 2000.
16. Van den Berg B, Brouwer WB and Koopmanschap MA. Economic valuation of informal care. *The European Journal of Health Economics, formerly: HEPAC*. 2004; 5: 36-45.
17. Brouwer WB, van Exel NJA, van den Berg B, van den Bos GA and Koopmanschap MA. Process utility from providing informal care: the benefit of caring. *Health policy*. 2005; 74: 85-99.
18. Pearlin LI, Mullan JT, Semple SJ and Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*. 1990; 30: 583-94.
19. Lazarus RS and Folkman S. *Stress, appraisal and coping*. New York: Springer Publishing Company 1984.
20. Central Statistics Office. Quarterly National Household Survey Carers Quarter 3 2009. 2010.
21. Robinson BC. Validation of a Caregiver Strain Index. *Journal of gerontology*. 1983; 38: 344-8.

22. Thornton M and Travis SS. Analysis of the reliability of the modified caregiver strain index. *Journal of Gerontology: Social Sciences* 2003; 58B: S127-32.
23. Deb P, Norton EC and Manning WG. *Health Econometrics Using Stata*. Stata Press, 2017.
24. Long SJ, Long JS and Freese J. *Regression models for categorical dependent variables using Stata*. Stata press, 2006.
25. Madden D, Nolan A and Nolan B. GP reimbursement and visiting behaviour in Ireland. *Health Economics*. 2005; 14: 1047-60.
26. Colombo F, Llena-Nozal A, Mercier J and Tjadens F. *Help Wanted?* 2011.
27. Trépel D. Informal Cost of Dementia Care – A Proxy-Good Valuation in Ireland *Economic and Social Review*. 2011; 42: 479-503.
28. Kenny RA, Whelan BJ, Cronin H, et al. The design of the Irish longitudinal study on ageing. The Irish Longitudinal Study on Ageing (TILDA), 2010.
29. Sullivan TM. Caregiver Strain Index (CSI). *Journal of Gerontological Nursing*. 2002; 28: 4-5.
30. Hansen T, Slagsvold B and Ingebretsen R. The Strains and Gains of Caregiving: An Examination of the Effects of Providing Personal Care to a Parent on a Range of Indicators of Psychological Well-Being. *Social Indicators Research*. 2013; 114: 323-43.